**Title:** Breaking ground in reducing the disparity of perinatal HIV transmission in Illinois

Health department/organization: Illinois Department of Public Health

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Goal: Increase HIV testing and documentation of results

Program type: Community outreach

Collaborators: Other HIV/AIDS program staff; HIV/AIDS surveillance; MCH part-

ners; other health department

# **Background**

African American infants carry an unequal burden of perinatal HIV infections. Sufficient data indicate that eliminating perinatal HIV transmission will take a multilevel prescription. Illinois is a state that is highly rural with 77 of its 103 counties classified as rural. Providing information via literature, follow up telephone calls, and face-to-face contact to providers in such a large area requires a well thought out coordination plan as we work to eliminate certain health disparities. Working with providers to change a set of beliefs or a way of thinking that determines who they would approach for HIV counseling and testing is an arduous task. At best only 70 percent of pregnant women in Illinois had HIV status recorded in their medical files at the time of delivery. Additional programmatic interventions were needed to ensure that wherever pregnant women contacted the health care delivery system they would be routinely offered counseling and testing and the results of the encounter would be documented in their medical records.

Maternal and child health advocates collaborated to ensure the passing of the Illinois Perinatal HIV Prevention Act. This act mandates that all pregnant women in the state of Illinois be provided HIV counseling and offered HIV

testing as early in the pregnancy as possible; HIV counseling and test results or the refusal for testing be documented in the prenatal, labor, delivery and newborn nursery medical records; and if a woman declines HIV testing for herself, her newborn infant will be tested for HIV unless the mother or legally authorized representative requests, in writing, that the newborn infant not be tested. While this law, coupled with new technology, provides the opportunity to essentially eliminate perinatal and pediatric HIV, it has also been challenging to implement. Members of the Perinatal Task Force developed a protocol to implement perinatal HIV rapid counseling and testing in labor, delivery, and nursery units in Illinois birthing hospitals.

# **Objective**

To initiate a program to provide HIV counseling and to offer HIV testing to every pregnant woman in Illinois and to document the results of that encounter in the woman's and/or newborn infant's medical record.

#### **Methods**

There are 3 distinct components of this project; (1) in high prevalence areas ("hot spots") across the state, community-based organizations (CBOs) are providing a myriad of services to

support prenatal HIV counseling, testing, linkage, and support services by using staff who are indigenous to the community; (2) state and community perinatal HIV elimination team members network with professional organizations whose members provide prenatal, perinatal, and postpartum care, and (3) Illinois Department of Public Health (IDPH) contracted with 2 agencies to develop a rapid counseling and testing protocol and provide training to all Illinois birthing hospital staff on HIV counseling and testing for women who arrive in labor and delivery units with unknown HIV status.

For the statewide community-based component, IDPH has contracted with 6 CBOs and one local health department in key areas across the state. These agencies are tasked with increasing their perinatal collaborations within their respective geographical areas. Each funded CBO is located within an area with HIV prevalence greater than 1 percent, high STD prevalence, high areas of poverty, health professional shortage areas, and increased street drug use. Funded agencies provide outreach services to providers who are not HIV-trained and provide community-based outreach to pregnant women who are at risk of becoming HIV-infected and are not receiving prenatal care. In addition, they provide HIV counseling and testing, network with an agency to provide pregnancy testing, and follow up to confirm positive referrals for HIV-specific prenatal care. The total population percentages served by these agencies are; 90 percent African American, 4 percent Caucasian, and 6 percent Hispanic.

Two agencies provide intensive case management for HIV-positive pregnant women. All agencies refer physicians not presently connected to major teaching hospitals to the Midwest AIDS Training and Education Center's (MATEC) Physician Core Seminar. Staff from each agency annually refer at least 20 direct care providers to seminars on HIV counseling and

testing. All grantees assure that all newly diagnosed HIV-positive pregnant women identified through services funded under this contract are linked into HIV/AIDS care and treatment services within 48 hours of receiving a confirmed HIV diagnosis through active linkage and referral to prevention case management or care case management services. The grantees provide the perinatal coordinator with a quarterly report of demographics on all newly diagnosed HIV-positive individuals identified through services funded under this contract in their region, detailing the following information: race, risk, county, and ZIP code. They also provide a list detailing which providers they have referred to MATEC for training.

The department perinatal coordinator has established collaborative relationships with 3 professional physician organizations and 1 nursing organization whose members provide prenatal, perinatal, postpartum, and newborn care. Each organization was contacted for their mailing list. An informational packet was sent to each member of the 4 organizations that contains a perinatal care and treatment manual, HIV prevention brochures relevant to the perinatal setting, posters, a copy of the recently passed Illinois HIV Prevention Act, and information on where to obtain information on documentation guidelines, if needed. A request was made to the director of the Department of Professional Regulation to include information on perinatal elimination projects in all physician, nurse, and advanced practice nurse re-licensing application packets.

A telephone poll was conducted March 1-15, 2004 and again March 23-30, 2005. The purpose of the poll was to ascertain how many prenatal, perinatal, and nursery providers were aware of the Illinois Perinatal HIV Elimination Act. The analysis of this activity is forthcoming.

The third component of the department's Perinatal HIV Prevention Program contains 5 key strategies and focuses on implementation of HIV counseling and testing in labor, delivery, and nursery settings: (1) training labor, delivery, and nursery staff to provide HIV counseling and testing in birthing settings, how to document the results of that encounter in pregnant women's medical records and support to develop protocols for implementing rapid HIV counseling and testing in every Illinois birthing hospital; (2) providing support to prenatal and perinatal providers with information and professional consultation, care, and treatment guidelines via the perinatal hotline; (3) providing referrals and linkages to care for the preliminary HIV-positive mothers and their newborn infants; (4) developing and establishing a perinatal surveillance database to document the outcomes of the aforementioned programming; and (5) developing and establishing a process to ensure the sustainability of the program through monitoring, reporting, and quality assurance activities.

## **Results**

- 36 providers were referred to MATEC for training
- 8,891 providers received packets of information
- □ 77 pregnant women were tested for HIV

- □ 4 pregnant women tested positive for HIV
- 4 HIV-positive pregnant women were referred to care
- ☐ 16 HIV-positive pregnant women are in case management (paid out of CDC funding)
- As of March 25, 2005, staff at 120 birthing hospitals have received implementation training on rapid HIV counseling and testing, 11 preliminary HIV-positive mother/infant pairs identified with 2 infants testing positive for HIV during the implementation process.

## **Conclusions**

The program has met its primary objectives. The lessons learned are:

- ☐ The need to develop, in conjunction with the community members, a culturally competent and theory-based educational testing adherence intervention
- Have a contingency plan for each component and pay close attention to how dollars are being expended
- Develop a process to maintain the integrity of interventions over time
- Developing and implementing a statewide sustainable perinatal HIV counseling, testing, and referral surveillance system remains a challenge that has not been resolved